breast cancer care

Breast cancer in families

Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do.

Visit **www.breastcancercare.org.uk** or call our free helpline on **0808 800 6000** (for Typetalk prefix **18001**).

Calls may be monitored for training purposes. Confidentiality is maintained between callers and Breast Cancer Care.

A large print version of this booklet can be downloaded from our website, www.breastcancercare.org.uk. It is also available in Braille on request. Call 0845 092 0808 for more information.

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Contents

Introduction

If you or one of your close relatives has been diagnosed with breast cancer, you may have concerns about what this means both for you and for other members of your family.

This booklet is for people who'd like to know more about breast cancer in families. It explains the three main risk factors for breast cancer, what is meant by a significant family history of the disease, and what to do if you think this may apply to you or to members of your family.

We hope this booklet answers some of your questions about breast cancer in families, and helps you find further sources of information and support if you need them.

Although this booklet is aimed mainly at women, much of the information is relevant to men.

Breast cancer risk

Research suggests that breast cancer is caused by a combination of many different things, but we still don't fully understand what the exact causes are, or why some people get breast cancer and some don't.

We do know, however, that some things can alter the likelihood of getting breast cancer, and these are called risk factors. For more information about risk in general see our Breast cancer risk: what it means to you booklet or visit our website at www.breastcancercare.org.uk

The three main risk factors for breast cancer are things that we can't do anything to change – gender, increasing age and significant family history.

Gender

Being a woman is the single biggest risk factor for developing breast cancer.

Breast cancer is the most common cancer in women in the UK, with over 44,000 new cases each year. Around 300 men each year are also found to have breast cancer. So if you're a woman, your risk of getting breast cancer is much higher than if you are a man.

Increasing age

After gender, age is the next most important risk factor for developing breast cancer – the older the person the higher the risk.

Most breast cancers (around 80 per cent) occur in women over the age of 50. Most men who get breast cancer are over 60.

The table below gives the estimated risk of developing breast cancer according to age, showing how risk goes up as we get older.

The lifetime risk of developing breast cancer is 1 in 9 for a woman who lives to be 90. This also means that 8 out of 9 women will not develop breast cancer in their lifetime, and that the risk for younger women is much lower.

Risk up to age 25	1 in 15,000
Risk up to age 30	1 in 1,900
Risk up to age 40	1 in 200
Risk up to age 50	1 in 50
Risk up to age 60	1 in 23
Risk up to age 70	1 in 15
Risk up to age 80	1 in 11
Risk up to age 85+	1 in 10
Lifetime risk (all ages)	1 in 9

“I’m in my 30s, and was starting to worry about breast cancer since the news seems to be full of younger women like Kylie who’ve had it. I’m more reassured now I know that most cases of breast cancer happen when you’re older.”
Gina

Significant family history

A small number of women may have an increased risk of developing breast cancer because they have a significant family history.

A family history records the past and present illnesses of your blood relatives (people related by birth rather than marriage) over several generations – for example, your mother and father, their brothers and sisters, their parents (your grandparents) and their brothers and sisters.

When taking a family history your mother's side of the family and your father's side are looked at separately.

A family history may be described as significant where there are, on the same side of the family:

- two or more close relatives who have had breast cancer
- one or more close relatives who have had breast cancer before the age of 40
- close relatives who have had breast cancer and others who have had ovarian cancer
- one close relative who has had breast cancer in both breasts (bilateral) or who's had breast and ovarian cancer
- a male relative who's had breast cancer.

However, most women do not have a significant family history and so their breast cancer risk is not affected.

Breast cancer in the family

Breast cancer is the most common cancer in women in the UK. So even if you have a relative with the disease it doesn't necessarily mean that you are more likely to get breast cancer yourself. Most breast cancers are not due to inherited (genetic) factors and do not affect the lifetime risk for other relatives.

In relation to the level of risk, breast cancer in families can usually be classed in one of three groups, and you may hear these groups referred to in a number of different ways:

- average risk (also called sporadic or near population risk)
- moderate risk (also called familial/raised risk)
- high risk (also called hereditary/increased risk).

If you're concerned about your risk of developing breast cancer it's important that you get professional advice tailored specifically to you and your family. By getting details of your family history (see *Assessing breast cancer risk* on page 17), health professionals can assess whether or not your risk of breast cancer is higher because of your family history and whether any further action is needed.

Average risk (sporadic or near population risk)

Sometimes this level of risk is referred to as near population risk because it means that your risk is the same or very similar to the risk for women who do not have a significant family history of breast cancer.

As we mention earlier, most breast cancers are not due to inherited (genetic) factors and do not increase the lifetime risk for other members of the family. This is likely to be the case in a family where one person has been diagnosed with breast cancer over the age of 50.

Moderate risk (familial/raised risk)

This is sometimes referred to as raised risk because it means that your risk is higher than average – but it's still more likely that you won't get breast cancer as a result of your family history.

A woman at moderate risk may have several relatives with breast cancer but no obvious pattern of the disease. In these families, although breast cancer may affect people in several generations, they tend to be affected at older ages.

Breast cancer in these families is not likely to be caused by high risk faulty genes (see below) and, although there may be lower risk genes involved, currently there's no genetic testing available for this.

It's possible that lifestyle and environmental factors may also influence breast cancer in these families, but at present there is no reliable evidence about this.

High risk (hereditary/increased risk)

A woman who has an increased risk of breast cancer is more likely to develop the disease in her lifetime than other women – although this does not mean that she'll definitely get breast cancer.

This level of risk is sometimes referred to as high risk, but even within this risk category there are several different levels of risk.

Women assessed to be at high risk usually have several close relatives with breast cancer over several generations – for example, grandmother, mother and daughter. Often these relatives will be affected at a young age.

This type of family history may be due to a faulty breast cancer gene. If genetic testing shows there is a faulty breast cancer gene in the family this is known as hereditary breast cancer.

Remember that even if a woman has a faulty breast cancer gene she will not necessarily develop breast cancer.

Only a very small proportion of women with breast cancer (5 to 10 per cent) will have a faulty breast cancer gene. The two genes that are most often found in hereditary breast cancer are called BRCA1 (BReast CAncer 1) and BRCA2 (BReast CAncer 2). Another gene that when faulty can lead to breast cancer is called TP53 (Tumour suppressor Protein 53), but it's much rarer for a woman to have a fault in this gene.

There may also be other genes that cause breast cancer that haven't yet been found.

There may be hereditary breast cancer in a family where there are people with:

- cancer in both breasts (bilateral breast cancer)
- both breast and ovarian cancer
- cancers that developed at a young age – for example under 40 – or certain childhood cancers.

Other factors include:

- a male relative with breast cancer
- an ethnic background where faulty breast cancer genes are more common – for example, people with Ashkenazi Jewish ancestry.

It's important to remember even if you or your family members appear to have a moderate or high risk, this doesn't mean you or they will definitely develop breast cancer.

Assessing breast cancer risk

If you're concerned about your risk the first step is to talk things over with a health professional.

Who you go and see first will depend on your situation. You can talk to your GP (local doctor) who may refer you to a family history clinic. If you have breast cancer yourself you can speak to a member of your specialist breast care team, or you may be referred directly to a genetic counsellor.

If your family history suggests that you are at moderate or high risk or if another family member has already had their risk assessed, you're likely to be referred directly to a specialist breast or genetics clinic. Here you'll have further assessment of your family history and be given specialist advice, including looking at the different ways of helping you to manage your risk.

> I thought I knew a lot about my family history, but when it came to detail I had to go and ask other relations. It's surprising how much you don't know about your family, particularly about what people die of. I even tracked down the death certificates of some of my granddad's elder sisters who died before I was born. It was more difficult and took much longer than I'd expected.
> Esther

Breast cancer family history clinics

Some hospitals run breast cancer family history clinics where you can see a nurse specialist or a doctor who will assess your risk based on your family history. Where these clinics are not available locally your GP may refer you directly to a Regional Genetics Centre.

At the appointment

Wherever you are referred, you'll probably be asked about the family history of all your blood relatives on both sides of your family. This includes your mother and father, sons and daughters, brothers and sisters, aunts and uncles, nieces and nephews, and grandparents.

Try and find out as much about your family history as you can from other relatives before your appointment. You may be asked to do this before being offered an appointment or you may be asked in the clinic. The person taking your family history will understand if you can't find all the relevant information.

You'll be asked about:

- what type of cancer/s have been diagnosed in your family
- how old each person was when diagnosed
- where in the body the cancer started
- whether the same family member has had more than one cancer (including cancer in both breasts)
- ethnic background
- whether the relatives with cancer are male or female.

If you're adopted or if you don't have any information about your biological family, your risk assessment can only be based on whatever information you have.

Remember that health professionals can't say for sure whether or not you will develop breast cancer, and your risk may change over your lifetime according to what happens to you and your relatives.

Whatever your breast cancer risk is, you'll be offered information and support that's relevant to your individual needs. This will include information about breast awareness and lifestyle choices, and depending on your risk it's also possible that you'll be offered screening, and/or genetic counselling and genetic testing.

If you're considered to be at high risk of breast cancer, have a complex family history or if further investigation into your family history would be helpful in understanding your risk, you may be offered a genetic counselling appointment at a Regional Genetics Centre.

What happens if I'm at average risk?

In a family where one person over 50 has been diagnosed with breast cancer, this is likely to be sporadic breast cancer. Most breast cancers are in this group. If the breast cancer in your family is sporadic, this means that family members are likely to have the same risk as other women in the general population (see page 9).

Even if your risk is not increased, it's important to be breast aware and go back to your GP if you notice any changes in your breasts. You can find out more about being breast aware in our Breast awareness booklet.

From the ages of 50 to 70 you'll be invited for routine breast screening every three years (this age range is likely to be increased to 47–73 in the future). After the age of 70 you can refer yourself every three years by contacting your GP or your screening centre directly.

> After my sister was told she had breast cancer I went to see my GP to find out about my risk, because my uncle also had cancer. She sent me to my local breast unit's family history clinic, where we went through all the people on both sides of my family who've had cancer. I was told that my risk wasn't affected by my family history, but if in the future anyone else in my family got cancer my risk might change.
> Denise

What happens if I'm at moderate or high risk?

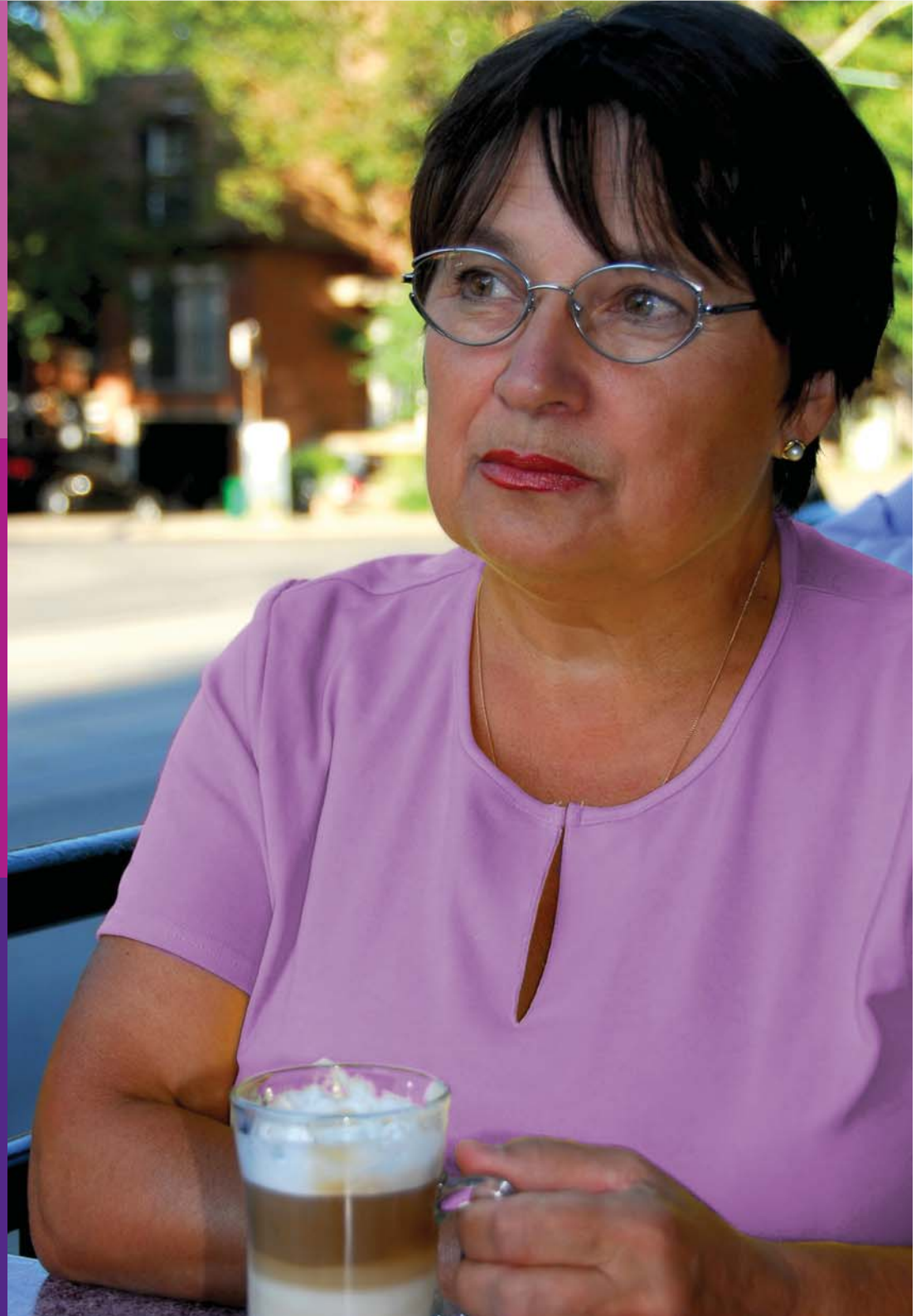
If your family history assessment suggests that you're at a moderate or high risk of developing breast cancer in the future, you're likely to be offered some of the following options.

Screening

The type of screening you'll be offered will depend on your age and your risk. Breast screening recommendations are based on national guidelines produced by the National Institute for Health and Clinical Excellence (NICE). See *Further reading* on page 35 for more about the NICE guidelines for women with a family history of breast cancer.

You may be offered regular mammograms (breast x-rays) between the ages of 40 and 49. From the ages of 50 to 70 (47–73 in the future) you'll be invited to attend for routine breast screening every three years. After the age of 70 you can refer yourself every three years by contacting your GP or your screening centre directly.

> My mum had breast cancer when she was 54, and now my sister, who's 50, has just been told that she has it. As I'm now 45 I'm going to ask my GP if I need to have mammograms now rather than wait till I'm 50.
> Pearl



Women at high risk (due to a faulty gene) may be offered mammograms earlier than 40 and/or Magnetic Resonance Imaging (MRI) screening, which uses magnetic waves instead of x-rays. In younger, high risk women MRI screening has been shown to increase the number of breast cancers correctly diagnosed.

Some women over 50 may need mammograms more often than once every three years. Your specialist genetics team will let you know if this applies to you.

Genetic counselling

If you're referred for genetic counselling at your appointment you'll see a genetic counsellor (a health professional with specialist knowledge about genes and hereditary illnesses) or a geneticist (a doctor with specialist training in genetics).

They can help you understand more about your family history, your risk of developing breast cancer and the options that may be available to you, such as genetic testing, screening and surgery to reduce the risk of cancer (risk-reducing surgery).

> I got really upset when I realised I was at increased risk. Luckily my genetic counsellor was there to support me and answer all my questions, and this made me feel better. Though I'm obviously still worried at least I'm better informed and know what my options are.
> Celia

If you don't know the answers to some of the questions, you may need to go away and find out more about your family history. It may also be worthwhile writing down any questions you have before your appointment, so you don't forget anything important. Also, you may want to take a friend or family member with you for support during your visit.

For many people, genetic counselling can be a very emotional time. You may feel anxious talking about your risk or your family's risk and what this means to you and those around you. It's important to remember that your genetic counsellor will have a lot of experience in this field and will be able to offer you support if you need it.

Genetic testing

Following your appointment with a genetic counsellor, genetic testing may be an option for you and other members of your family. Only a few people will be offered genetic testing and, even if it is an option for you, you may choose not to be tested.

Genetic testing is only available through a genetics department and following genetic counselling. Genetic counselling involves discussion of the implications of the test and the possible outcomes, generally over several visits.

First stage

This involves taking blood from someone in your family who has been diagnosed with breast cancer or ovarian cancer and checking this for one of the known faulty genes. If you have had breast cancer yourself then the blood may be taken from you. The results from this test can take several months.

If none of the people in your family who have had breast cancer are still alive, it may on rare occasions be possible to have a genetic test. Your genetic counsellor will be able to advise you on the options available.

It can be hard to find a faulty gene, so sometimes a genetic test is inconclusive. This means that it's possible for there to be a faulty gene somewhere, even though it hasn't been found.

"Out of four sisters, three of us have had breast cancer. My oldest sister also had ovarian cancer, and died when she was 41. I was worried about my daughter and my four granddaughters and so had a genetic test to see if I had one of the breast cancer genes. Unfortunately the result was inconclusive, so we still don't know if there's a faulty gene in the family. My daughter, who's 42, has a mammogram every year just in case."
Maggie

Second stage

If a faulty gene has been found in the person with breast cancer, it means that a genetic test is available for other relatives to see whether or not they also carry the faulty gene. The results of this don't usually take so long because it's known where the faulty gene is located.

If you're found to carry a faulty breast cancer gene, it's important to remember that you won't necessarily go on to develop breast cancer. However, you do have a higher risk of developing the disease than people without a faulty gene.

If you don't have the faulty gene identified in your family then you have the same risk of developing breast cancer as other women in the general population (see page 9).

"My gran died of breast cancer at the age of 44 and both my mum and sister have breast cancer so they were tested to see if they had one of the breast cancer genes. They were found to have BRCA2. I've since been to the family history clinic and I'm waiting for the results of my genetic test."
Gemma

Risk-reducing surgery

If you're at high risk of developing breast cancer your genetic counsellor will discuss the possibility of surgery to reduce your breast cancer risk. This involves removing both breasts (bilateral mastectomy) and is called risk-reducing surgery.

Reconstruction of both breasts is usually offered at the same time, which means rebuilding the breasts using an implant and/or tissue from another part of the body. For more information see our Breast reconstruction booklet.

Although having a bilateral mastectomy significantly reduces the risk of developing breast cancer, it's important to realise that it cannot remove the risk completely.

Some women who carry a faulty gene are also at higher risk of developing ovarian cancer. Having the ovaries and fallopian tubes removed by surgery (bilateral salpingo-oophorectomy) before the natural menopause (when your periods stop) has been shown to reduce the risk of both ovarian and breast cancer.

If you are considering risk-reducing surgery you may find it helpful to read Cancerbackup's Risk-reducing breast surgery booklet (see page 35).

Insurance

Currently if you've had a genetic test for breast cancer you don't have to disclose the result when you apply for insurance, such as life or health insurance (under a certain amount). However, insurance companies currently ask about your family's medical history and if you have a significant family history of breast cancer you may be charged a higher premium.

Clinical trials

There are several clinical trials underway to find out more about breast cancer and family history. If you have genetic counselling it's possible that you'll be asked to take part in one of these trials. For more information on clinical trials in general see our Clinical trials and breast cancer factsheet.

In the future

It's important to go back to your GP if your family history changes – for example if another relative develops breast or ovarian cancer. If necessary you may then be referred to a breast or genetics clinic for further assessment and observation.

Your feelings

Concerns about inheriting breast cancer are common among women who've had relatives with breast cancer.

If you've been advised that you are at average risk you may feel reassured and relieved. However, it's still important that you go back to your GP if your family history changes or if you have concerns about your own breasts.

Finding out that you're at moderate or high risk of developing breast cancer can cause many different emotions. You may feel more anxious about your breast health, or afraid of what the future holds for you as you approach the age at which a relative was diagnosed.

Breast cancer not only affects you but also your relationships with other members of your family. If you have children you may find that you have concerns about their health – or new anxieties about having children. All cancer genetics clinics have genetic counsellors who you can talk to about how you're feeling. There are also a number of organisations that may be able to support you during this time (see *Other organisations* on page 37).

Can you reduce your breast cancer risk?

Certain risk factors can be influenced by changing some of the ways you live your life. Lifestyle changes that may reduce your risk are:

- keeping your weight within healthy limits, especially after the menopause
- taking regular exercise and keeping active
- eating a well balanced diet, with plenty of fruit and vegetables
- limiting how much alcohol you drink.

For more information on risk factors visit our website at www.breastcancercare.org.uk

Be breast aware

Whatever your risk and lifestyle choices, by being breast aware it's more likely that if you do develop breast cancer it will be found as soon as possible. This means it's more likely to be treated successfully.

By being breast aware you'll become familiar with your breasts and the way they change throughout your life.

You will know better than anyone how your breasts look and feel normally, so if you do notice a change, see your GP or breast specialist. You can find out more about being breast aware in our Breast awareness booklet.

Further reading

CG41 Familial breast cancer – Understanding NICE guidance

National Institute for Clinical Excellence, London, 2006
ISBN 1 84629 299 9

Available at www.nice.org.uk/CG041 or from the NHS Response Line: telephone 0870 1555 455 and quote reference number N1131.

Risk-reducing breast surgery

Cancerbackup, London, revised 2007

Available at wwwcancerbackup.org.uk or call 020 7696 9003.

Help from Breast Cancer Care

We hope this booklet has helped you to understand more about breast cancer in families.

If you'd like to talk to someone about breast cancer in your family, or any other subject related to breast cancer, call our helpline free on 0808 800 6000 (for Typetalk prefix 18001).

You can also visit our website at www.breastcancercare.org.uk where you can email a question using our Ask the nurse service, or chat with other people via our online discussion forums.

Other organisations

Association of British Insurers

51 Gresham Street, London EC2V 7HQ

Telephone: 020 7600 3333 (ask for Consumer Helpline)
Email: info@abi.org.uk
Website: www.abi.org.uk

Provides a leaflet called Insurance and genetic tests: what you need to know.

Breakthrough Breast Cancer

www.breakthrough.org.uk/about_breast_cancer/family_history

Provides information and a discussion forum for those concerned about their family history of breast cancer.

Cancerbackup

3 Bath Place, Rivington Street, London EC2A 3JR

Office: 020 7696 9003
Freephone helpline: 0808 800 1234
Email: info@cancerbackup.org
Website: www.cancerbackup.org.uk

Cancerbackup is the leading national information and support charity for people affected by cancer. Services include a helpline staffed by specialist cancer information nurses, a website, cancer information booklets and local information centres. All Cancerbackup services are free to people affected by cancer.

Cancer Counselling Trust

1 Noel Road, London N1 8HQ

Telephone: 020 7704 1137
Email: support@cctrust.org.uk
Website: www.cancercounselling.org.uk

Offers confidential counselling to individuals, couples and families who are affected by cancer. Provides a face-to-face and telephone counselling service.

National Hereditary Breast Cancer Helpline

Information Centre, St Anne's Cottage, Over Haddon, Derbyshire DE45 1JE

Telephone: 01629 813000 (available 24 hours)
Email: canhelp@btopenworld.com
Website: breastcancergenetics.co.uk

Provides help and information for those concerned about a family history of breast cancer. Also sends out an information pack, and holds a database of women who are happy to talk to others in a similar position.

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Breast Cancer Care is committed to equal opportunities and access for all.

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For all breast cancer or breast health concerns call our free, national helpline on **0808 800 6000** (for Typetalk prefix **18001**) or visit **www.breastcancercare.org.uk**

Your donations allow us to provide publications like this one free to people affected by breast cancer. If you'd like to make a donation, please send your cheque to: Breast Cancer Care, RRKZ-ARZY-YCKG, 5–13 Great Suffolk Street, London SE1 0NS. Or donate via our website at www.breastcancercare.org.uk

Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do.

Visit **www.breastcancercare.org.uk** or call our free helpline on **0808 800 6000**.

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